AUGUST 2025

LAMPost

LAM ACTION
Supporting women with
Lymphangioleiomyomatosis

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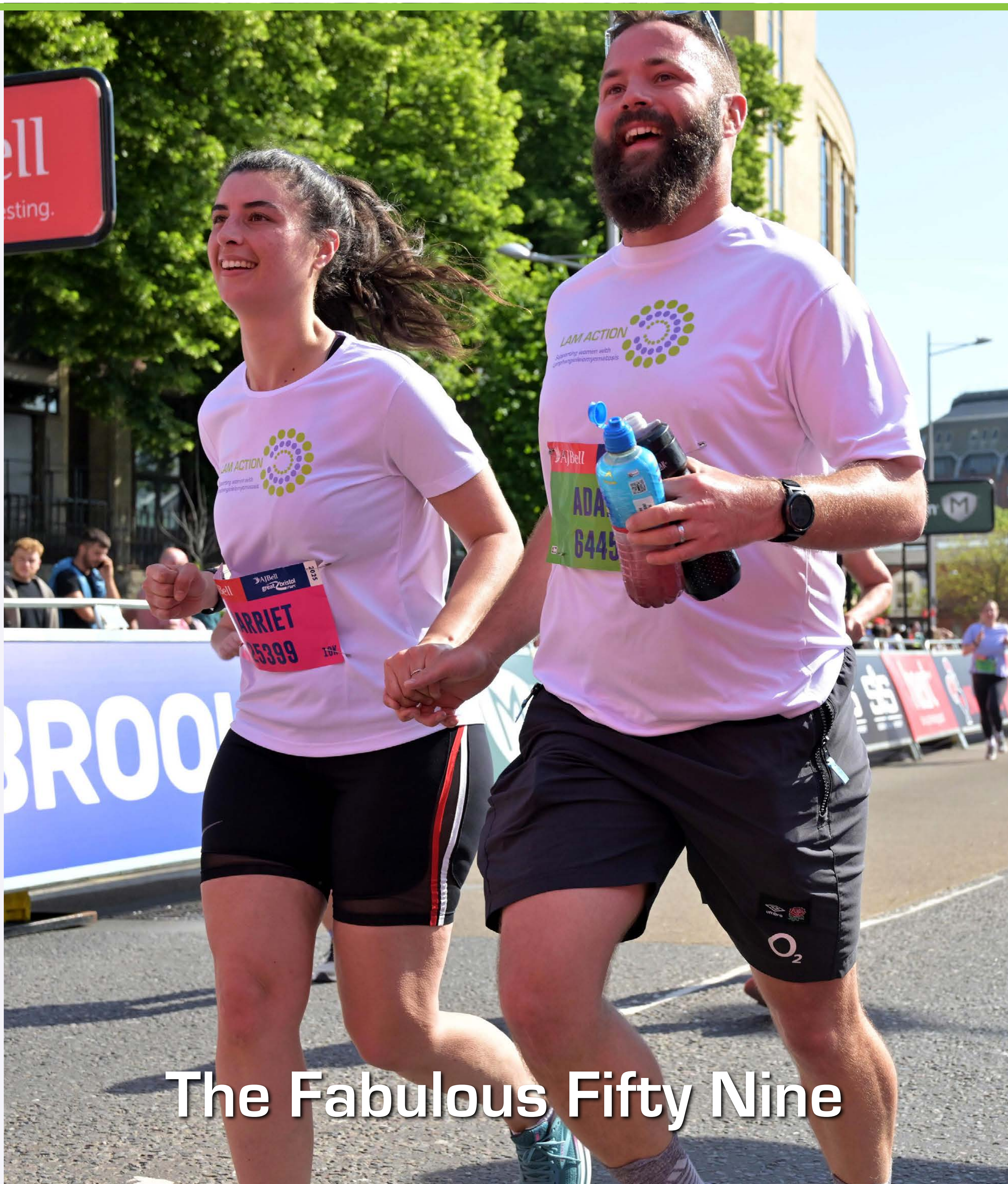


The Fabulous Fifty Nine

From the Editor's Desk

Usually for the summer editorial you will find me moaning about the weather, or more specifically, the lack of good weather. This year I don't suppose many of us can complain, though if anything it has been too hot, and maybe we should be careful what we wish for! I hope you have managed to stay cool and the successive heatwaves have not adversely affected your breathing.

You will notice that this edition of LAMPost is rather longer than usual and the reason for this is that we have reproduced the results of the recent online survey into how LAM Action is measuring up to the stated aims of supporting women with LAM in the UK. The results make for interesting reading, and while the old adage that you will never please all of the people all of the time holds true, the overwhelming majority of responses were very positive, and there were also some excellent suggestions as to how we may improve the levels of support that we currently offer.

There are of course the usual updates and reports on our magnificent army of fundraisers, who have more than answered the call and there have been some absolute corkers recently that have either involved stunning feats of endurance or incredible efforts in organisation and planning that have left us all quite speechless at the lengths some of our lovely supporters will go to raise funds and also, just as importantly, awareness of the condition and we take our collective hats off to you all.

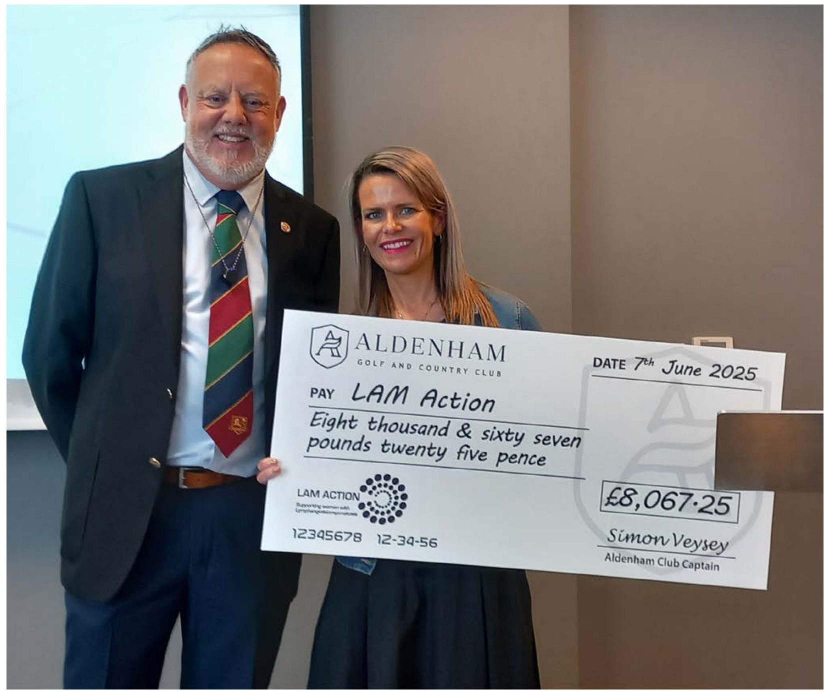
It's not just the big-ticket events though, we really appreciate the smaller events and the regular donations and standing orders that keep us ticking over and allowing us to keep funding the dedicated team at Nottingham, and some of you will have heard the latest research updates from Dr. Debbie Clements at the Annual Meeting in Watford back in June.

Talking of Annual Meetings, we are already planning the 2026 meeting and investigating ways we can incentivise and make attendance more feasible for our members. Those who use the LAMTalk UK Facebook page have already been canvassed on potential venues and funding possibilities, please cast your vote if you haven't already done so. We hope to confirm details of next year's meeting by the autumn so please stay tuned for more information.

A big thanks to everyone who contributed to this edition of LAMPost. We will return just before Christmas, with a publication deadline of **December 10**, please email any articles or other contributions to: lampost@office.lamaction.org.

Until then enjoy what's left of the summer and very best wishes to you all,

John



A massive **THANK YOU** to Simon Veysey, former Club Captain at Aldenham Golf and Country Club in Hertfordshire, for the fantastic amount raised on behalf of LAM Action.

Simon came along to the Annual Meeting in Watford in June and presented a cheque for **£8,067.25** to LAM Action Chair Leanne Lillywhite, the total raised throughout Simon's tenure as Captain, having nominated LAM Action as the club's Charity of the Year.

Big thanks also to everyone who supported the fundraising, and the members and club officials at Aldenham for their kindness and generosity.

LAM Action Annual Meeting 2025

On Saturday, 7th June, we welcomed people to the LAM Action Annual Meeting at the Leonardo Hotel, Watford, near London. While it may not have attracted as many people as previous meetings, we were treated to a series of outstanding presentations and discussions. Progress in the understanding of LAM, and research into the disease, appears to be accelerating, and we were all left with a great deal of hope for the future.

As ever, one of the biggest benefits of the meeting is the opportunity to meet and chat informally with other women with LAM, their friends and their families, and this camaraderie and these connections just can't be replicated online. It was wonderful to see faces old and new, both at Friday night dinner and at the meeting itself.

A summary of the programme is below, but there were broadly two main themes.

The first is that, largely thanks to Prof. Simon Johnson's dedication to our cause and growing reputation over decades now, our very rare condition is getting both more attention and more research funding for his Nottingham team. Both Simon and Dr Debbie Clements covered some of these developments in their talks. Recently, LAM has also been included in two important multi-disease research programmes; LAM is one of the exemplar diseases in the new LifeArc Translational Centre for Rare Respiratory Diseases, and is also one of the conditions being studied in a specific node of the UK Rare Disease Research Platform dedicated to mTOR pathway diseases. Therefore, we were honoured to have Dr Sam Barrell, LifeArc's Chief Executive Officer, and Prof. Joe Bateman, who leads the mTOR Pathway Disease node, to talk about the work of these two projects, and how LAM fits in. Dr Cormac McCarthy also presented on the research into LAM being done by his very active group in Dublin. It was incredibly uplifting to hear these professionals talk with so much passion and enthusiasm about their work.

The second theme we tried to cover in this meeting was to provide support, guidance and practical information for women and families living with LAM. Therefore, sessions led by physio and rehabilitation specialist Rick Porter, and by clinicians Prof Simon Johnson and Dr Gauri Saini, invoked questions and animated discussions.

Many thanks to all who contributed to the success of the meeting: the excellent speakers, who gave up part of their weekend to be with us; those who baked cakes, donated raffle prizes and manned the stalls; trustee David Mercer and his team who recorded the presentations for future dissemination; and the organising committee, who ensured that the meeting content was interesting and that the event went smoothly. Also, thank you to everyone who attended - from all corners of the UK and beyond - and participated with such enthusiasm; we hope you found it informative, helpful and encouraging.

Finally, I hope you will join me in thanking people who work on our behalf all year round: the helpful, friendly, and knowledgeable LAM Centre staff; the Nottingham research team; Jill Pateman, our LAM Action coordinator; and the Executive Committee of LAM Action who give up their time to support the LAM community.

We look forward to seeing as many people as possible next year. As you may be aware, we have recently surveyed LAM Action members and other women with LAM about the format, location and possible subsiding of our annual meetings. This will help inform decisions about future meetings. We hope to make details available very soon, but next year's meeting is likely to take place over the weekend of 5/6/7 June 2026, so please save the date! Thank you.

Gill Hollis

2025 Annual Meeting Programme

Timing	Topic
09:30	**LAM Basics** Prof Simon Johnson - Director of the National Centre for LAM; Professor & Head of Respiratory Medicine, University of Nottingham; Co-director of the Rare Cystic Lung Disease Collaborative Network
10:00	**Welcome & AGM** Year in Review / Financials / Election of Trustees
10:30	**Prevalence of LAM, and other research** Online presentation by Cormac McCarthy - Associate Professor and Deputy Director, Clinical Research Centre, University College, Dublin
11:00	Coffee break
11:10	**Lucy Falconer Keynote Address – Patient Engagement in Rare Respiratory Disease** Dr Sam Barrell, Chief Executive Director of LifeArc
12:00	Lunch
13:05	**mTOR Pathway Diseases Node and LAM** Prof. Joseph Bateman, Kings College London, lead investigator for the mTOR Pathway Diseases node, part of the UK Rare Disease Research Platform
13:30	**Recovering Pulmonary and Physical Fitness After Illness** Rick Porter - Bsc Physiotherapy and MSc Advanced Rehabilitation, together with LAM Centre physicians
14:00	Coffee break
14:10	Break-out sessions: • **Family and friends discussion** • **Breathing techniques**
14:40	**Research Developments** Dr Debbie Clements, Scientific researcher for LAM, Nottingham
15:10	**Is "This" Related to LAM?** – A discussion of various symptoms and problems many of us experience, and what we should do about them. Led by LAM Centre clinicians with questions and input from LAM patients **General Q&A**
16.00	**Close of Meeting**

Joy Wadsworth and Helen Sabin

The LAMPost Editor, Jill Pateman and Clare Lyon

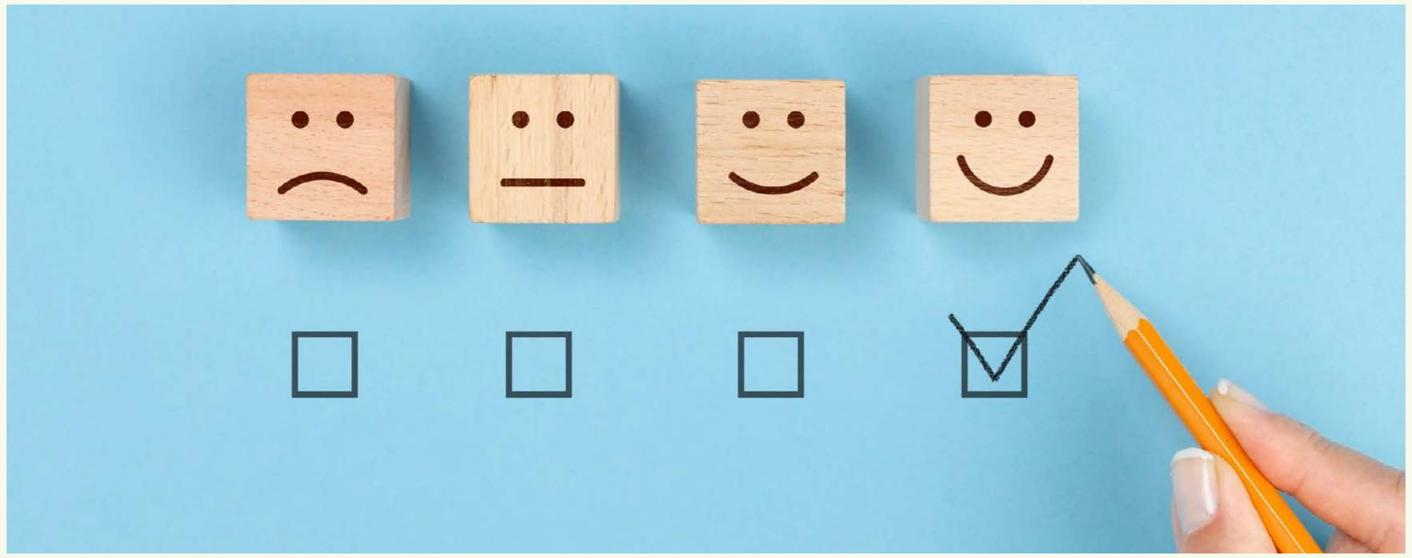
Jo Pisani and Dr. Sam Barrell, LifeArc CED

Rick Porter demonstrating breathing exercises

Dr. Debbie Clements with a research update

Trustees Sally Merritt-Collins and Sarah Sharples

LAM Action Effectiveness Survey



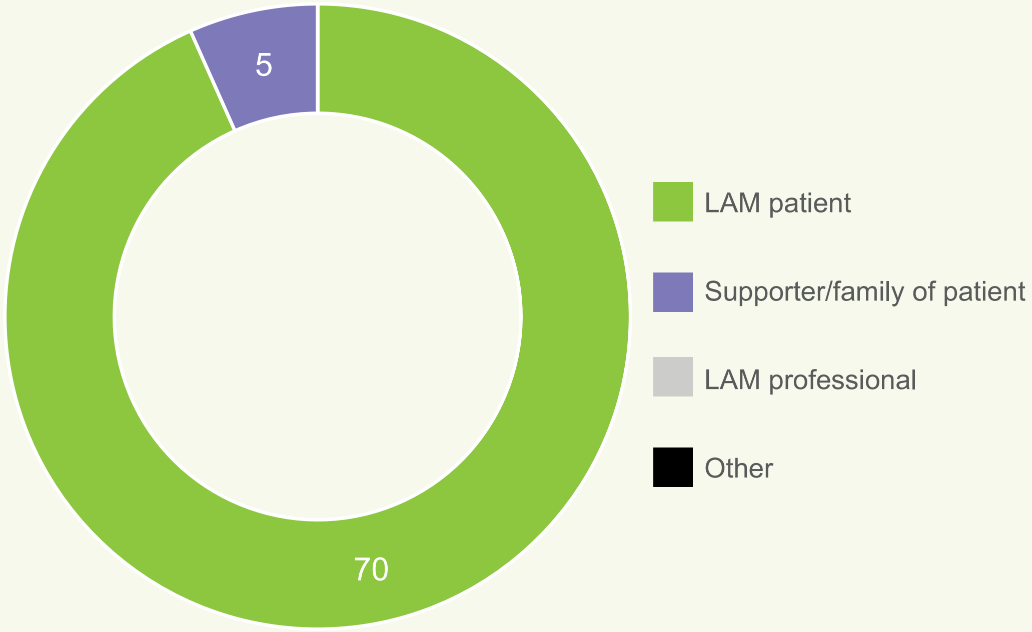
A big thank you to everybody who took the time to complete the recent survey as to how LAM Action are performing, and whether we are meeting our stated aims when it comes to supporting LAM patients.

We had a good response, with 75 people taking part. While the results show pleasing levels of satisfaction with most of our services, we recognise that there are a few areas where improvements could be made, and the few surprisingly negative bits of feedback will be followed up.

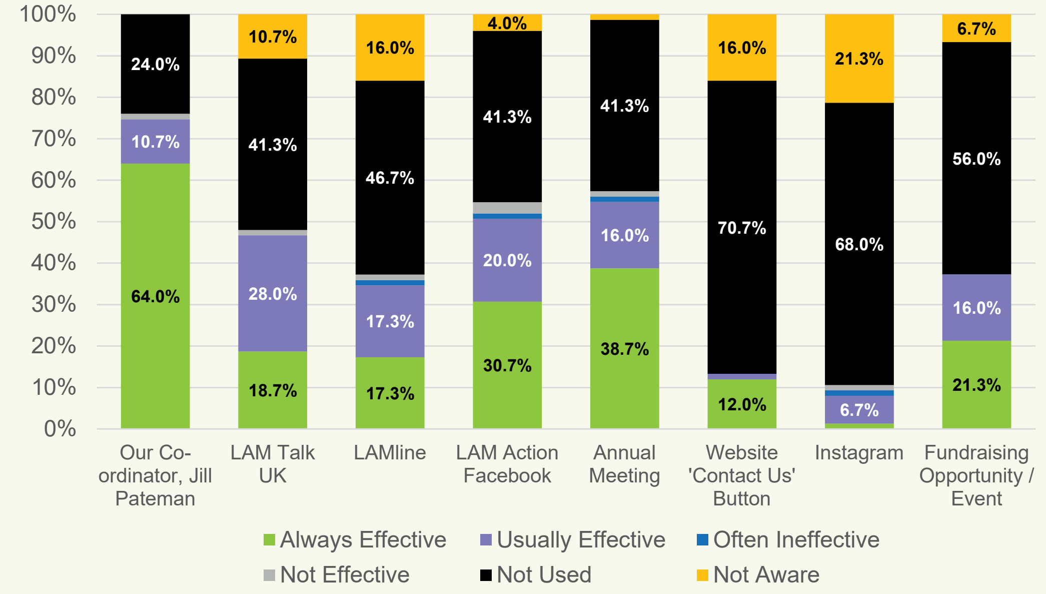
Breaking the data down, 99% of respondents identified as female and 1% male, with 91% identifying as white, and 9% representing other ethnicities. By age group, 23% were aged 21-50, 63% aged 51-70, and 14% 71 and over.

Thank you also to LAM Action Trustees Sally Merritt-Collins and Adam Davidson for all their hard work with the survey, which we hope you will agree was a very useful exercise in helping us shape our future approach.

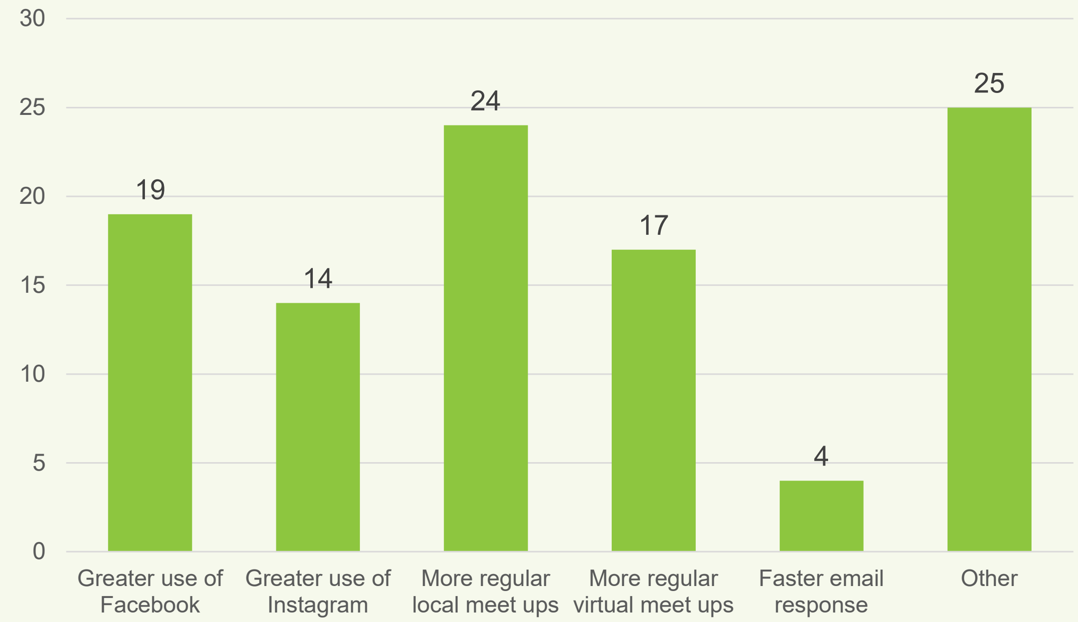
Breakdown of Respondents (75 responses in total)



Please rate the channels of communication that you have used to talk with LAM Action



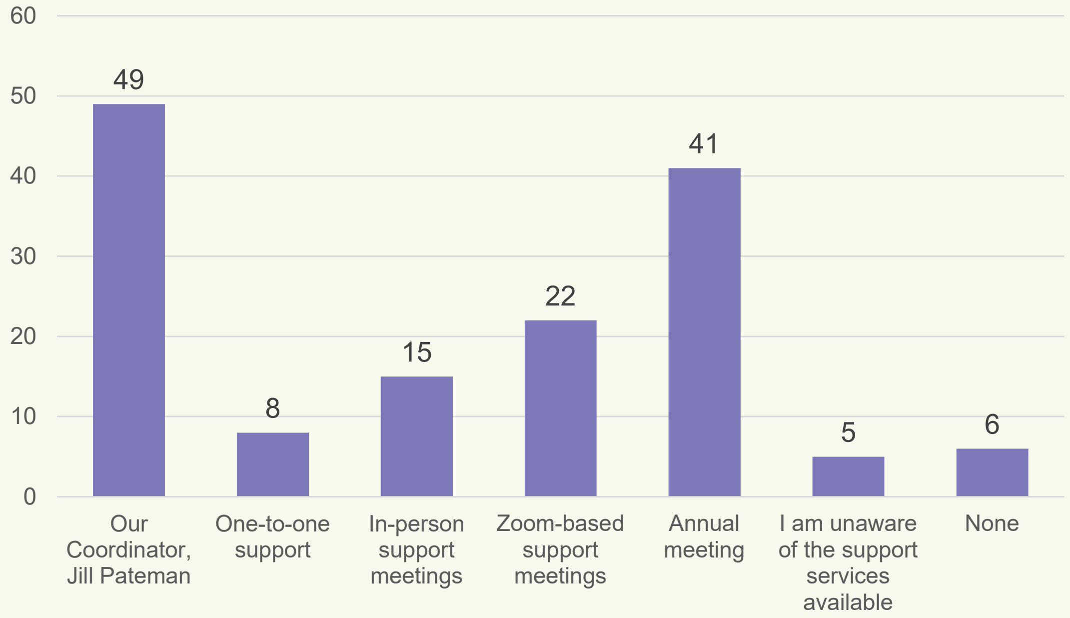
What changes (if any) do you think would make engaging with us easier or more effective?



'Other' responses included:

- Symptom led groups (virtual)
- A knowledge hub of resources covering relevant topics, i.e., travel insurance, menopause, exercise, when to seek medical advice etc.
- Use of X or Bluesky
- Clarity about what you want to engage about, what is the objective?
- Membership email updates (not just LAMPost) include the monthly fundraising opportunities/social media links
- Structured managing your LAM programme. I am really struggling to remember to take my meds on time and it's a constant struggle to motivate myself to exercise. Need accountability. I have used one to one support informally but maybe this could be promoted more. Maybe training people in skills in managing a chronic condition and patient advocacy.
- More patient meetings – half yearly
- More info about research studies and findings
- Perhaps having a conference in North West* for a change instead of always having to travel (*actual city changed for anonymity reasons)

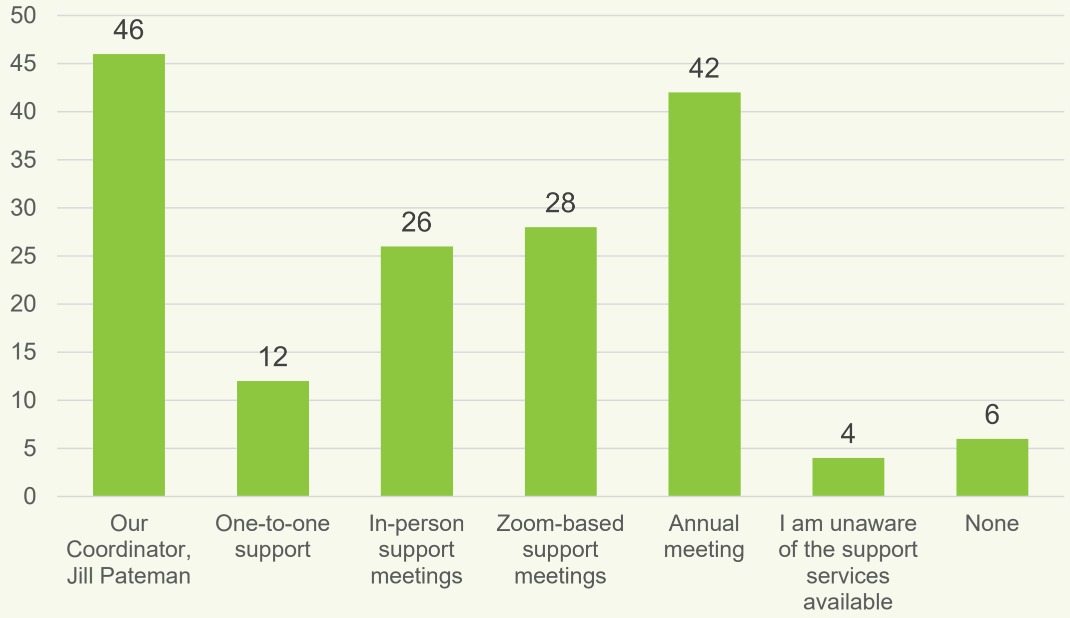
Which of our support services have you used?



If you selected 'None' above, please provide a reason for your selection:

- I have contacted the nurse who is very helpful
- I have not required support
- Promote one to one support more. Train people in managing chronic conditions and patient advocacy.
- Not sure of what is offered
- Felt support from LAM team at QMC was sufficient
- I have not yet needed this support

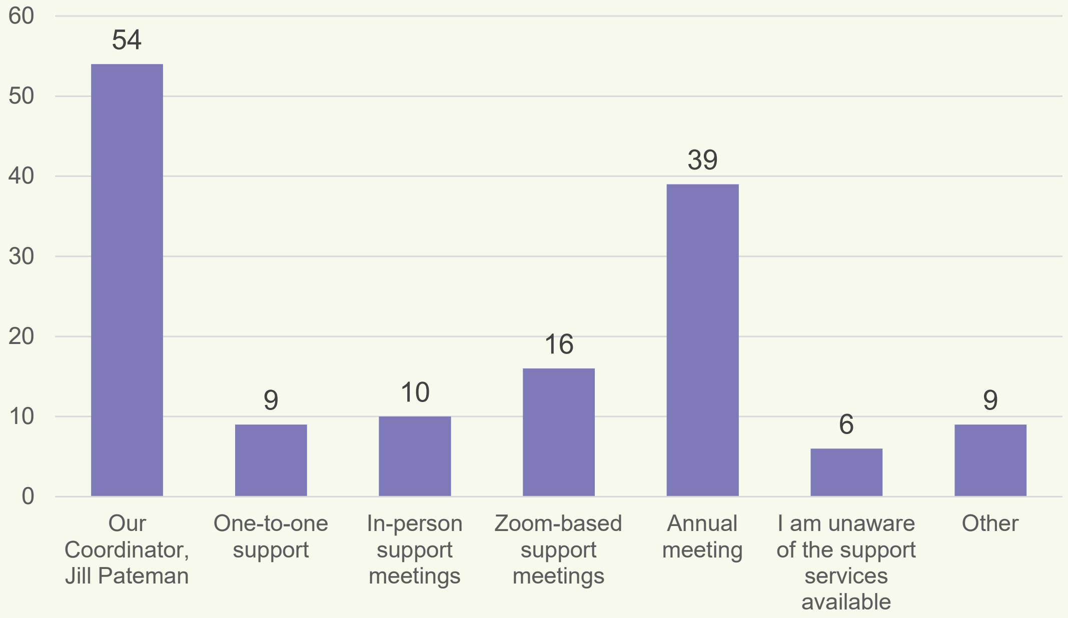
Which of our support services do you think you may use in the future?



If you selected 'None' above, please provide a reason for your selection:

- F2F support group not welcoming
- I don't anticipate needing support
- Currently asymptomatic
- Unable to get out and about
- Many medical issues of which LAM is minor, and little/no support required

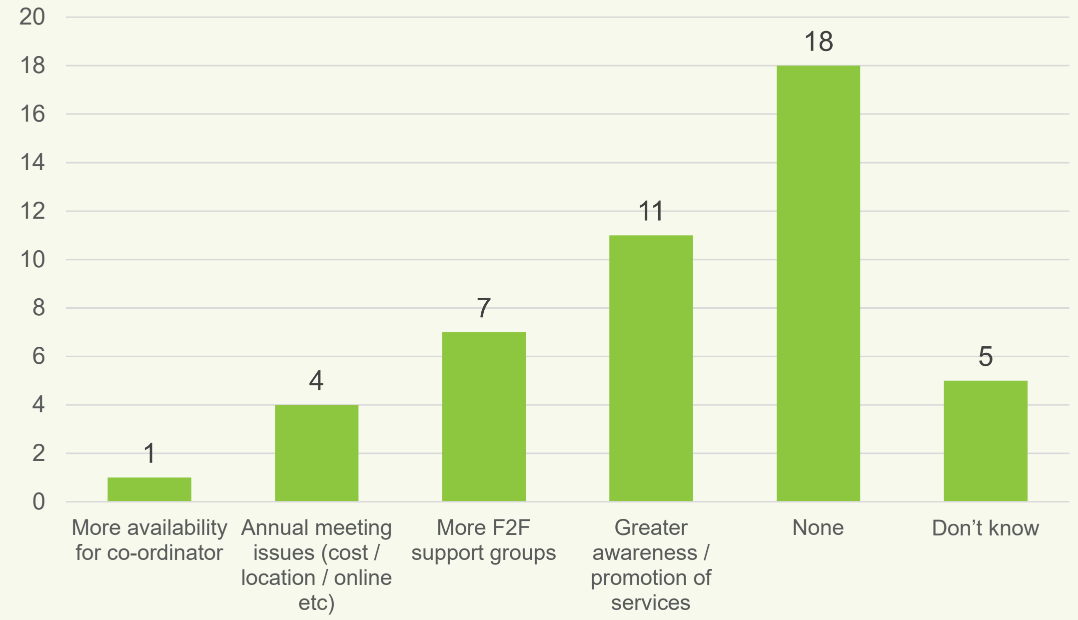
Regarding support services, what do you feel we currently do well?



'Other' responses included:

- I think it is difficult to say, I have been less engaged recently, so I have not really been on my emails or Facebook for updates
- I appreciate there is support offered by LAM Action, but it appears very limited
- I'm not sure what the in-person support meetings are

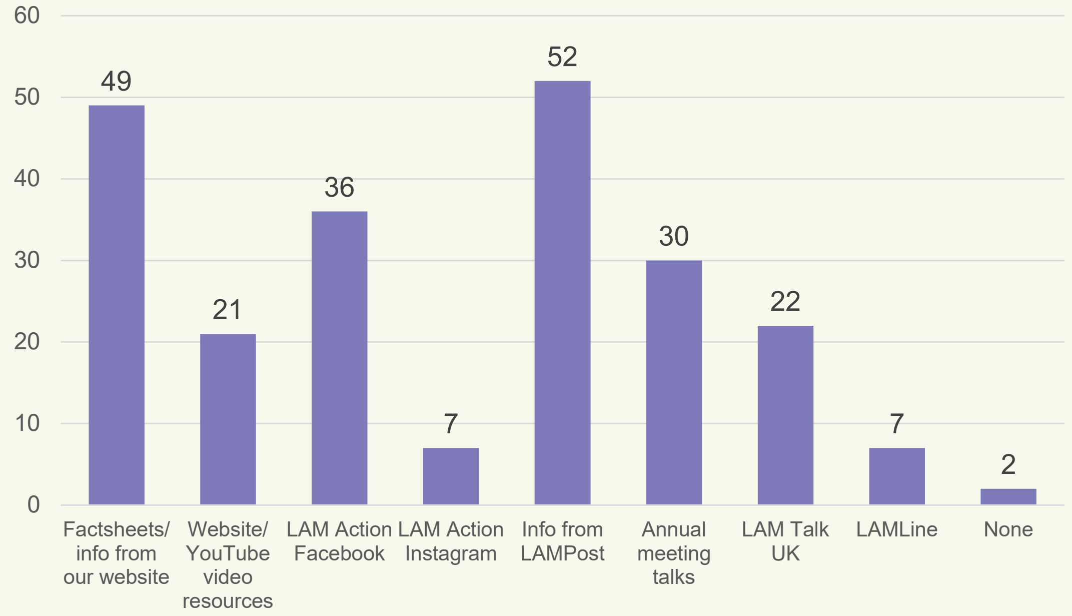
What improvements do you think we could make to improve our support services?



If you selected 'None' above, please provide a reason for your selection:

- Local F2F Groups are good
- Happy with current support
- No change needed
- No immediate thoughts
- You do a very good job
- Facebook is a quick, easy form of communication and I like it as it is a closed group

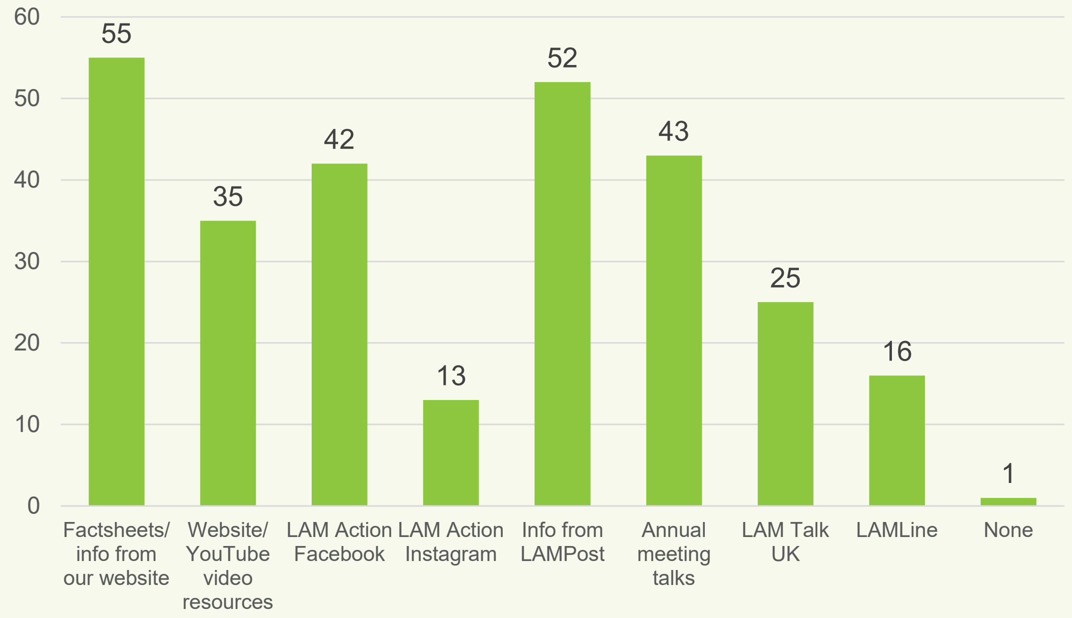
Which of our sources of information do you currently use?



If you selected 'None' above, please provide a reason for your selection:

- I find the LAM Foundation has more accessible resources. I have accessed all the YouTube annual talks in the past, LAMPost seems to include mostly articles on fundraising rather than information about the disease. I was unaware of Facebook, LAM Talk and LAMLine until about 4 years after joining LAM Action.
- None of the above is easily accessible

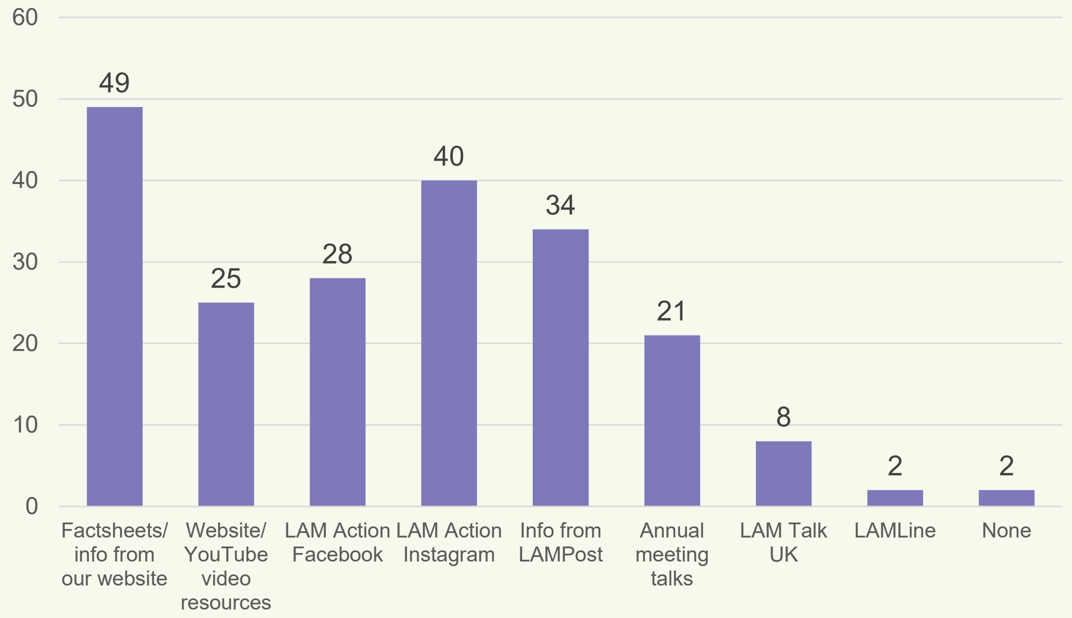
Which of our sources of information do you think you may use in the future?



If you selected 'None' above, please provide a reason for your selection:

- Depends how you update resources, as outlined in previous answers

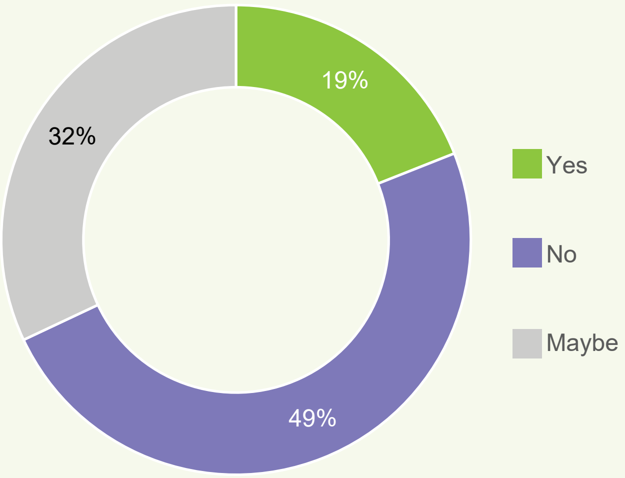
What sources of information do we currently do well?



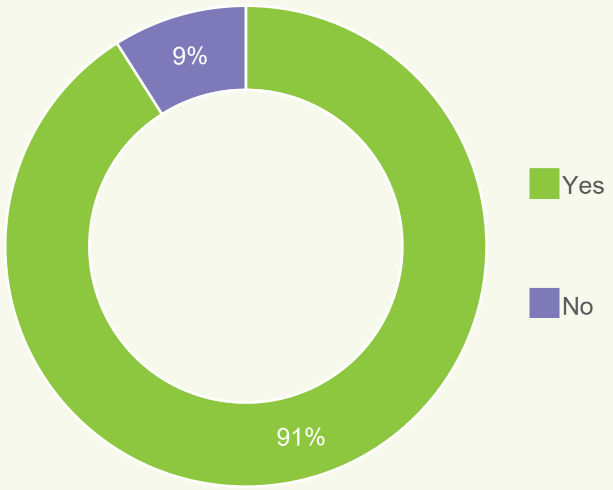
What else (if anything) do you feel we should be doing to provide support, encouragement or information?

- Vary location of annual meeting
- More lifestyle advice/encouragement x3
- More health-related advice x2
- Member of wider incurable disease support groups?
    - e.g. Macmillan support cancer patients, Marie Curie support terminally ill patients but it would be lovely to have a national group for incurable disease patients. LAM is incurable but doesn't fit into any national support network. If it's becoming more recognisable and diagnosed more it would be nice to have an overall support network to help with mental health and signposting to financial help, PIP forms, continuing work etc.
- Research talks to be saved online
- A library of resources
    - A knowledge hub of resources covering relevant topics i.e., travel insurance, menopause, exercise, when to seek medical advice, etc.
- More website features
    - The website is good, but I think it would benefit from having more information on there. The American site has a big handbook with different chapters. Something like that could be useful.
- More F2F support groups, e.g. Essex/Cambridge/Hertfordshire border
- Better use/more active on social media, especially Instagram. Sharing stories/experiences. It's always great to hear about fundraising but also let the LAM community about ways to stay healthy, how to stay safe with LAM (e.g. during extremely hot or cold weather), ways of staying active etc.
- Annual meeting online
- More online webinars
- We need to share more stories and experiences on social media, reaching out and being relevant. Being more active before the in-person meeting. Better collaboration with other global LAM communities, perhaps offering grants to be able to attend meetings. Having Q&A webinars and searching for info and ideas from clinical disciplines.

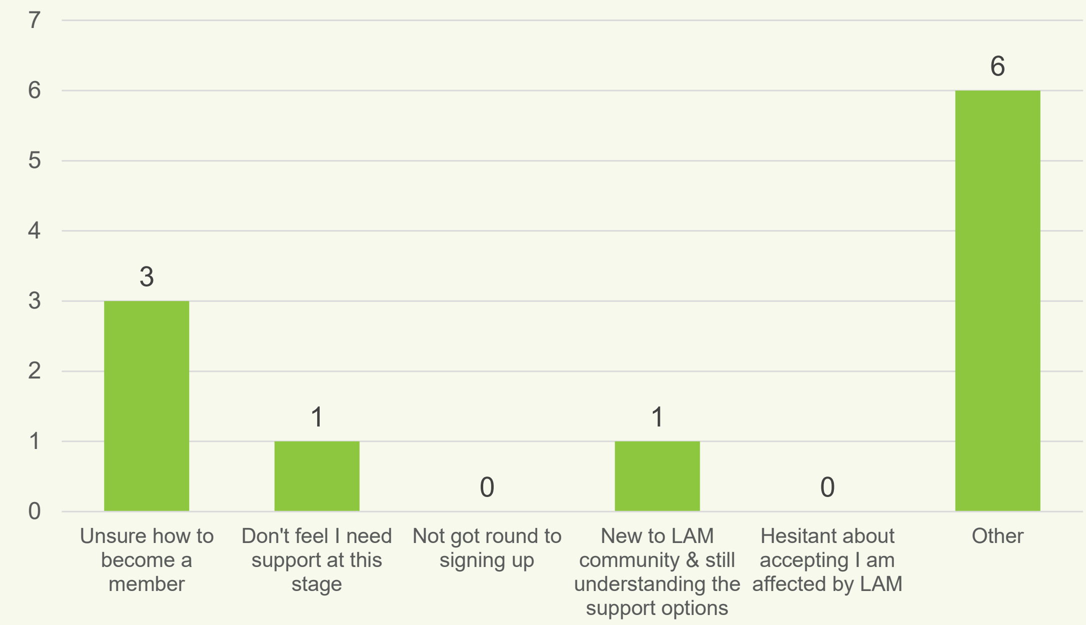
Because LAM is so rare, LAM Action is a self-help group run mainly by a small number of volunteers. Are you able to offer help to LAM Action and to other people with LAM?



Are you a member of LAM Action?



If you are not currently a member of LAM Action, please can you tell us why that is?



In Memory

IRIS BASSI

On 28 April 2025, the LAM community lost one of its most committed and determined advocates – Italian patient, Iris Bassi.

Iris was passionate about bringing European LAM patients, clinicians and researchers together. In 2008 she established a patient group in Italy, LAM Italia Onlus. Two years later, she organised an international LAM meeting in her hometown of Udine, near Venice, attended by clinicians and patients from around the world, with hard-fought funding from drug companies. She went on to develop strong links with the European Lung Foundation (the patient arm of the European Respiratory Society), and at the 2014 European Respiratory Congress in Munich, there was a LAM Patient Priorities workshop and a scientific symposium on LAM.

Iris had many talents; as well as being an accomplished linguist, yoga played an important part in her life and her art was fabulous. But her greatest love was her son, Nicolas, whom we've watched grow up to be a talented musician and photographer.

In November 2024, Iris was assessed for a lung transplant but had become increasingly unwell. She is survived by her parents and her son.

LORNA CROOK

All of us at LAM Action were very sorry to hear of the passing of Lorna Crook on 1st May 2025. Since being diagnosed with LAM over 30 years ago, Lorna kept in close contact with many other women with LAM, both in the UK and overseas. She contributed to our online group often, and was always very encouraging, supportive and kind. Even recently, when she was facing her own health problems, she was still lovely and welcoming to everyone, particularly the newly diagnosed, giving them good advice and that special thing - hope. As one of our recently diagnosed members commented in her tribute: "Lorna encouraged me last year. She was so kind and helpful. In the 30 years she had spent with LAM, she had built a meaningful and beautiful life, which really inspired me."

Lorna lived near Glasgow and was very close to her family. She is survived by her mother, sister, two sons and their wider families, including one grandson. Her passing was quite sudden, and our thoughts are with all her family and the wide circle of friends she leaves behind.

Gill Hollis

Goodbye and Thank You!

Ilona Leighton-Goodall

Tess Hill

Harriet Davidson

The LAM Action Committee would like to bid a very fond farewell and express our deep gratitude to the above former Trustees who have stepped down in the last couple of months. Ilona, Tess and Harriet had all been stalwarts in recent years and we will miss their knowledge, enthusiasm and can-do attitudes that made them such valued members of the Committee. Thank you for all your hard work on our behalf and very best wishes from us all!

Oli Takes on The Spine Race for LAM Action

The Start Line

Oli Wingrave has taken on many challenges over the years to support LAM Action, completing both Ride London and the London Marathon. But all of those pale into insignificance compared to his latest heroic effort which very few would even contemplate putting themselves through, let alone actually taking part. Read on, but it's really not for the fainthearted!

My Connection to LAM: My sister Kate, who lives in Australia, was diagnosed with LAM 15 years ago. In 2022 she had a double lung transplant. Life with LAM and post-transplant has not been easy. Kate was 'on oxygen' for many years prior to her transplant and by the time she did have her transplant, she didn't really have much lung function left. So I decided it would be nice to raise money for LAM Action whilst doing the Spine Race.

About the Spine Race: Every year in winter (January) and summer (June) a run along the length of the Pennine Way (the spine of Britain) is organised by the Spine Race. This is a 431km / 268 mile non-stop endurance race (10,700 metres of elevation gain), setting off from Edale in the Peak District and finishing in Kirk Yetholm, Scotland. I took part in the Summer Spine, which started at 8am on the 15th June 2025.

https://www.thespinerace.com/

We had 6 ½ days to get to the finish line. There was a checkpoint roughly once a day in which you could stop (maximum of 6 hours), have something to eat, drink, get a brief sleep and re-stock you backpack (from a fairly large 'drop bag' we were permitted to leave at the start of the race, this was then transported from checkpoint to checkpoint. There were 5 checkpoints along the route).

In our drop bags we had spare clothes, food, first aid kits, sleeping bag etc. As there were large distances between checkpoints we had to be self-sufficient with food and water. There was also quite an extensive minimum kit that we had to carry in a backpack along the route. This consisted of food, water, first aid items, head torch, map, compass etc.

You are not allowed any crew or pacers or outside help, other than being permitted to stop in a shop, café or pub along the route.

Main things to try and avoid, in terms of injuries, are getting your feet wet and avoiding the feet staying wet (trench foot), trying to avoid blisters (caused by rubbing / friction) and shin splints (caused by impact, often going downhill a bit too harshly).

(I write this article 1 week after the race, but I do believe I have put everything in the right order).

The Start: First checkpoint (CP) was at Hebden Bridge – 73km away from Edale in the Peak District. We had 24 hours to get there and leave (as you have to leave a checkpoint within the 'cut off' time, not just arrive).

157 people set off on a sunny morning in Edale. Nervous energy propelled us along, as did fantastic views. As is normally the case with this type of event we all went off a little quicker than we should have done, caught up in the excitement of the event. Not long into the jog was a climb up Jacobs Ladder, a short sharp climb up some steps, but nothing compared to some other climbs on later days.

A couple of burger vans along the way were very much welcome. A brief stop at these including the well-known 'Nicky's Food Bar', just after the M62 and off again.

As it was the start of the run, we were all quite bunched up together, so I got chatting to a few people at different stages, often sharing stories of what other races they had ran.

I arrived to CP1 in 15 hours and tried to sleep for 1 hour, but just lay in a bunk bed, which I thought would happen, but nevertheless it was good just to let the body rest for an hour. After a quick shower and much faffing with re-stocking my backpack I left the checkpoint after arriving 3 ½ hours earlier. As such I left the CP with a good amount of time before the cut off.

Second CP was the long one, 102km to Hadraw (CP2). 36 hours to get there and leave.

This was certainly a real slog but with wonderful views along the South Pennines. It felt like the most remote section of the whole of the Pennine Way but it was also quite overcast and in places (often high up) it was very misty so that probably added to the sense of isolation. For the vast majority of sections I ran by myself but I was happy to run alongside different people for a few kilometres here and there.

Roughly halfway along the checkpoint there was the promised land of a Co-op at Gargrave (116km into the run). I can safely say pretty much every 'Spinner' would visit here. Inside we would find all sorts of goodies but almost too much choice. I stood for a god number of minutes trying to decide what to eat and drink. After getting my brain to work and mumbling something to the lady behind the counter (it was a bit of shock meeting real people after being out in the wilderness) I ate, drank and carried on.

The last 20km or so were pretty tough. Up along a never-ending notorious road called Cam Road, which seemed to go on forever. Up and up it went, with no end in sight. By this stage I was also starting to get a bit tired, not having slept in almost 2 days. I saw Father Christmas by the side of the trail and a few miles later the devil. Were they real or were they hallucinations. After supposedly seeing some people having a picnic alongside the road at 2am and hearing sheep talk, I thought I had better press on and get some sleep as soon as possible.

I eventually arrived to Hadraw (CP2), 25 ½ hours after setting off from CP1. Around 20 people had dropped out by this stage, most apparently due to going out to fast, others due to various ailments – normally feet and legs. A sleep (of around 2 ½ hours), much faffing with kit, eating, more faffing and suddenly I have just 15 minutes to get out of the checkpoint. When they say you have a maximum of 6 hours at each checkpoint they were not joking.

Before you leave each CP you have to have a kit check. Halfway through the kit check, I had just 5 minutes to leave. If I have not left within the next 5 minutes, I will be disqualified (I arrived at the checkpoint 5 hours 55 minutes ago). "Where are your two antiseptic wipes" I am asked, I can see one, where is the second, found it. Now I need to show eight paracetamol, I have six. "What have I done with the other two"? 3 minutes to go. "Think! Where are they?" I said to myself. Got them, I had them in another pocket.

Sunrise just after leaving CP1, Hebden Bridge

Kit check done. Now it's time to run, I have to get out of the checkpoint (and out of the field where the checkpoint is) in 3 minutes, I run bare foot across the field, shoes and roughly packed backpack in hand, with 2 volunteers running behind me with the rest of my kit. Phew just made it time. That would have been very annoying, being excluded from the race for that reason. I made a conscious note to never let that happen again…

Next CP a relatively easy 54km away (CP3 at Middleton Teeside). Again 24 hours to get to the CP and back out, plus I had built up a bit of extra time in hand.

The weather was starting to heat up. Mid 20's but a spectacular day. Wonderful views across the valleys and also the highest pub in Britain to reach, the Tan Hill Inn. This was roughly halfway through the stage so a great place to stop for 1 hour. Us smelly runners / joggers / walkers, had our own room in the pub. Probably for the best, we must have smelt pretty badly. After a burger and a pint of Coke, onwards and upwards for another 25km.

Past reservoirs and farms and amazing views I edged closer to Middleton Teeside, arriving as it had just gone dark. Greeted by a lovely volunteer who took me inside the CP. On the menu was a chicken korma – very nice indeed. The option of sleeping in a bunk bed or a tent was offered. I wrongly opted for a bunk bed. Bad idea as it was near to the room where people were being treated by the doctors – needless to say there were numerous cries of pain and yelps and in the bunk beds lots of snoring and farting. I think I drifted off to sleep at some stage but with the clock ticking I need to get up and head off to the next CP.

CP4 at Alston YHA – 59km away and with the promise of showers I made my way along the North Pennines.

Not a massive amount of possible food and water places along the way today, so I took a full 3 litres of water with me, and some squashed up food from my drop bag. The temperature was in the high 20's, which I have to say I did like. It added to the challenge. I was a bit silly in not wanting to stop the day before to apply sun cream and now started to feel my skin burning a bit, but not much I could do about it.

Along the route, perhaps the most impressive waterfall called Cauldron Snout, was soon to arrive. The scene is building for some time as you have to walk along a river to get to it. Some technical sections, climbing over big rocks. To reach the top, it was a scramble up the side of some rocks, which was great fun.

A place called High Cup Nick (which is a very large curved chunk out of the land or resembling a high pipe) was at the top of a hill. I sat / half slumped here for 10 minutes. Again, amazing views. I stopped by a lovely little waterfall across the path. Another runner and I enjoyed the views, stopping now and again to take it all in. Almost like something out a film set like Lord of the Rings, with panoramic views all around.

A lovely village called Dufton arrived (260km into the jog or 29km for the section). I could have stayed here for some time, but alas there is also the need to keep moving. At the start of the village the Spine Race safety team did a mandatory check that I was still 'with it' and making sense – the lady put on her records I was in 'excellent condition'. I wouldn't have used the word excellent, but nevertheless I did feel pretty good. I then carried onto a lovely café in Dufton called the Post Box Pantry. A had fantastic homemade burger and a couple of cans of fizz and chocolate bars, then off again, into the blazing sun. Before I left someone had pointed out where we needed to climb up to, which was a large weather station in the distance. Gulp. Better get going then.

Further along is a refuge hut called Gregs Hut, empty when I arrived but in the Winter Spine race there are spicy noodles on offer. More spectacular views. Each day just kept getting more amazing.

Also on the route was the highest point in England. Cross Fell. I had heard a lot about it, but it didn't seem to be too hard to be fair. A lot of up and down but I reached the top and I carried on. I arrived at Alston late at night, had a shower, the first for a few days, and had something to eat (their famous Lasagne) then tried to get some sleep. Alas after a couple of hours I didn't manage to get any, so I left. After a bit of trouble navigating and a head lamp battery that didn't work, I was on my way around 2am into the darkness.

CP5 at Bellingham – 64km away – 20 hours to get there and leave.

Onto Bellingham and along a section of Hadrian's Way. Must have been the hottest day so far, touching 30 degrees. On paper not much in the way of food and water refill stops so I carried 3 ½ litres of water. As day broke, the sun came up and the scenery was once again amazing.


High Cup Nick, after CP3, Middleton Teeside


Hadrian's Wall, in-between Alston and Bellingham

34km into the section (or 322km overall) the Waltown National Park appeared as if by magic and a visitors' centre. As the centre wasn't open for another 40 minutes (I arrived at 9:20am and it opened at 10am) and being pretty tired, I had a quick sleep for 20 minutes then got up, devoured most of the food in the shop, then onwards.

What a scorcher but also what incredible sights Hadrian's Wall had to offer. It was a section of the wall that was quite raised, so the views across the valleys were spectacular. There was a lot of up and down along the wall, but I really enjoyed it.

I cannot completely remember what was after Hadrian's Wall but not far from the checkpoint is a well-known but unofficial stop at Honeystead Farm, with a friendly farmer who likes to feed hungry Spinners. No complaints here. Stocked up once more, just another 10km to Bellingham.

Bellingham arrived, as thankfully did some sleep, but I missed my alarm and overslept. Only 1 hour and 40 minutes to the maximum stay of 6 hours. Sounds a long time but I do faff around with 'admin', e.g. stocking up my backpack from my drop back. I left with 15 minutes to spare at around 1am for the final section.

66km to the finish at Kirk Yetholm in Scotland. 26 hours to get there (plus whatever time I had built up ahead of the cut offs, which was around 17 hours, so I had plenty of time and could just walk it in if I wanted).

There was only really a couple of water stops on the way today. I set off in the darkness, out of Bellingham then into the wild. I am sure for a couple of hours someone was behind me, but they never did catch up. Along the way I passed more and more Spinners, whose legs and feet were pretty shot. There were some fantastic downhill sections which I ran down. My competitive side kicked in and I must have passed around 20 people across this section. I arrived at a water point, but it was swamped with midges, so stopped briefly for a cup of tea and top of water and I was off again.

It started to get quite hilly leading up to Hut 1 (water available) and Hut 2 (water on offer). The Huts are very basic refuges. Again, I passed some more people, who were ahead of me for some miles, but when I next looked, I saw them collapsed by the side of the path. But they were OK, just one of the sights along the route. That would be me in about 1 hour, for a brief 10-minute sleep.

It wasn't long now to Kirk Yetholm and the finish. I was really thirsty and couldn't wait to have some water and a Coke. It was also mainly downhill into the finish, but of course not before a surprise hill about 500m from the end. Finish line in sight, I ran across the line and as is tradition in the Spine race touched the wall of the Border Hotel in Kirk Yetholm, which drew this crazy week to a finish. 5 days 8 ½ hours later (16:30 on Friday). 27 ½ hours to spare until the cut off (20:00 on Saturday). 102 finished and by some miracle I finished 43rd. I hadn't thought for a second where I would finish. As I am normally down the back of the pack. 43rd was pretty good in my books.

The Pennine Way has a reputation of being quite boggy but aside from just a small few sections, the route was completely dry (thanks to the hot weather and not much rain in the weeks beforehand).

I would more than happily do the Spine again but with so many other long distance ultra runs, I will probably opt for a different one next year.

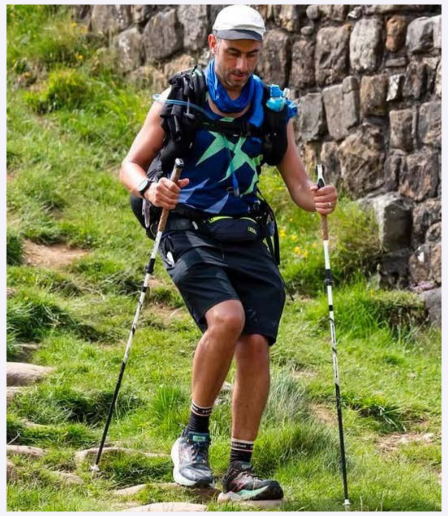
There are 8 short videos on YouTube of each day's action here if you wanted to find out more:

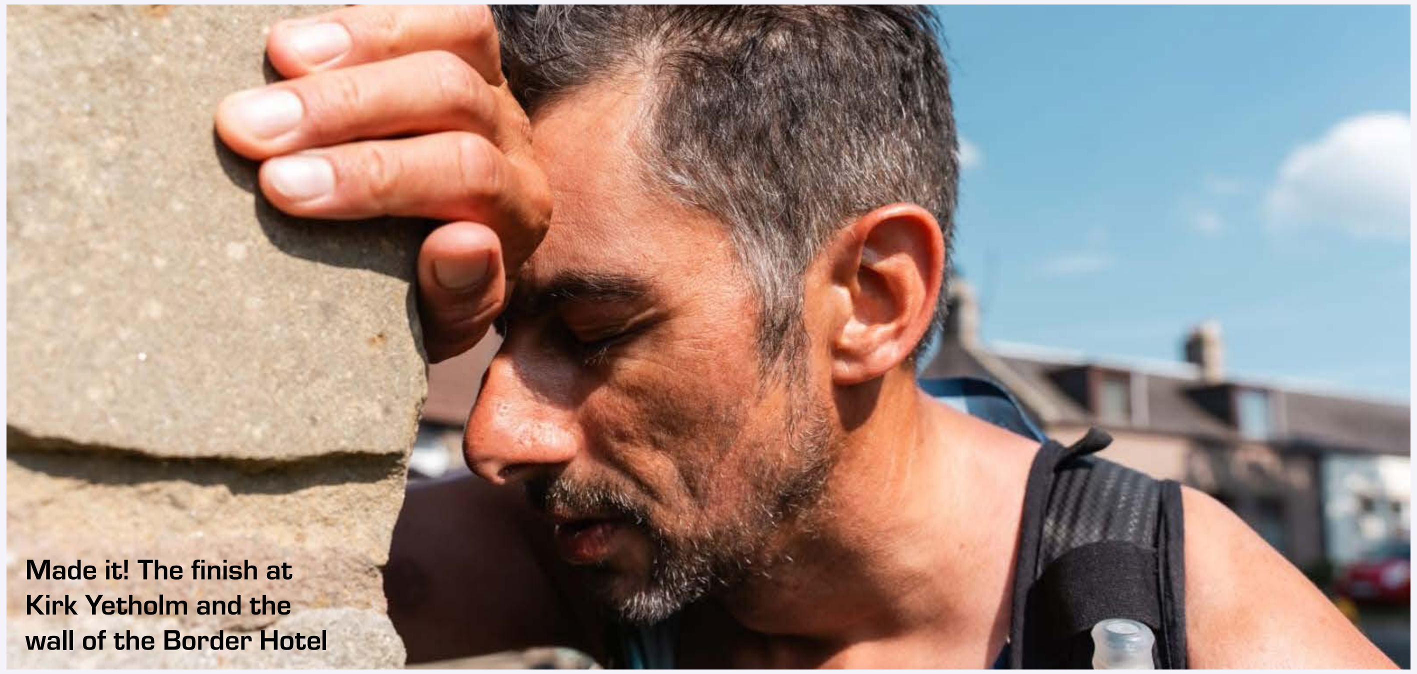
https://www.youtube.com/@SpineRace

Editor's Note: Well done Oli, you absolute superstar - talk about going above and beyond, what an epic feat of endurance, thank you!

If you would like to support Oli's fundraising please visit the link below:

https://www.justgiving.com/page/431km-pennine-way-jog





Made it! The finish at Kirk Yetholm and the wall of the Border Hotel

London Marathon 2025

On 27th April 2025 LAM Action had 7 runners taking part in the London Marathon.

The first of them to finish was **Ellenor Rixon** - a friend of Julie Mullins. Ellenor completed the 26.2 miles in a great time of 3 hours 33 minutes and raised £2055 in the process.

Next in was **Andy Judge**, a barrister from London, running for LAM Action for the third time. Andy's total was £1000.

Sasha Tsymbal who's originally from the Ukraine had asked to carry over his place in March because of a hip injury, but decided to run at the last minute. Despite the pain he managed a very creditable time of 4 hours 21 minutes and brought in £565 in sponsorship.

Simon Fairbrother is a friend of LAM Action trustee Sally Merritt-Collins. This was his first marathon, but he's previously run a half marathon and cycled the 100-mile Ride London for LAM Action. Simon raised £2456 for the charity.

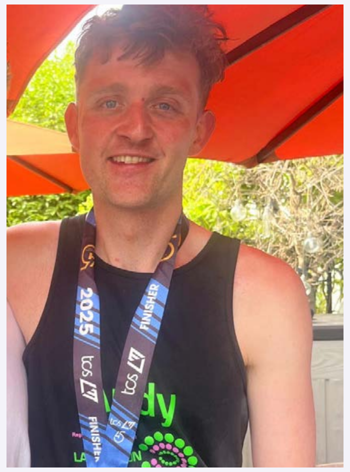
Jamile Muller is a legal psychiatrist from Brazil, part of a group who travelled to the UK to run for small medical charities. Jamile reached her fundraising target of £2000.

Mark MacNaughton's wife, Jurgita has LAM. Mark also suffered from an injury during training but he managed a very creditable time and raised £3225 for LAM Action.

We believe our final runner, **Eleanor Ward** is the first woman with LAM to complete the event. Her time was 6 hours 46 minutes and she brought in an awesome £4390 for taking on the challenge.

Congratulations and thank you to all our Marathon runners for all their hard work in training, fundraising, and the event itself. In total they raised an amazing £15,691 for LAM Action.

David Mercer



Bristol Fashion for a Month of Fundraising


Some of the Fabulous 59 waiting to set off

On Sunday May 11th, 57 registered runners took to the streets of Bristol alongside Adam and Harriet Davidson to run 10km in aid of LAM Action. Adam is a LAM Action Trustee, and Harriet is a former Trustee and LAM patient.

Over 24,000 runners took part in the event, running both the 10k and the half marathon. The morning started off warm, with clear blue skies and the sun beaming down on the runners, and as the start time of 8.30am was approaching, it was getting hotter and hotter. After a group warm up on the start line, the runners set off in three waves of decreasing pace, with a healthy LAM Action representation in each.

There were plenty of entertainment zones including drag queens and DJs, and a huge number of supporters lining the route encouraging runners onwards (whether known or not). Due to the heat, there was also an optional cool shower to run through at the 3km mark, which we are reliably informed was needed. The route, which is predominantly flat, does have one short, but taxing incline towards the end. At the foot of this hill was the Avon Fire and Rescue Service showing their support - by aptly blasting out 'Running Up That Hill' by Kate Bush.

Our fastest female of the day was Hal Brooks-Johnson who completed the race with a new personal best of 51 minutes and 25 seconds. And our fastest male on the day was Connor Morton, who completed the 10k in a time of 41 minutes and 46 seconds. But it wasn't just about the fastest, we are hugely proud of every one of our runners who completed the event amid taxing conditions, with many achieving PBs. We ran the course together and completed it in a very respectable time of 01:05:08.

There then followed an incredible finish to a month of fundraising for LAM Action in the form of a charity pub quiz night, hosted by Harriet's mum. We had been donated some wonderful prizes from so many local businesses and were absolutely blown away by the support we received for our two raffles. The evening was sensational, and we also had the honour of being joined by another LAM patient, named Louise Haynes. Months of hard work paid off spectacularly, and we are extremely delighted to say we have to date, in total, raised **£9288.80** for LAM Action!

Words cannot describe how grateful we are for everybody's generosity - it truly is honourable, and we have had an absolute blast. Well done and big thanks to everyone!

Harriet and Adam Davidson

Great support from both old and young


Proudly sporting their LAM Action colours


Time for a well-earned breather

Adam with Harriet's mum


A full house for the pub quiz